
JOIN DEMENTIA RESEARCH NEWSLETTER

SPRING 2017



GPs play a vital role in supporting people with dementia and those with concerns about their memory and cognition. They are not only well placed to ensure people access the most suitable healthcare but can also play a key role in raising awareness of the importance of research and how to get involved. I am therefore pleased to introduce General Practitioner Dr Peter Arthur as our guest editor for this edition.

Professor Martin Rossor, National Director for Dementia Research at the National Institute for Health Research

As a General Practitioner of 27 years, I have met many people who live with a diagnosis of dementia and know first hand how hard it can be for them, and for their loved ones. As the average age of the UK population increases, it is clear now more than ever, that dementia research is of vital importance.

There is lots of different research going on throughout the UK and I always recommend to my patients that they consider registering with Join Dementia Research to see if they are eligible to take part in any studies in their area. At times it may seem as though you are not able to participate as much as you would like or that you are not matching with many studies, but I urge all volunteers to stick with it and to regularly update and check their account in order to make sure they are getting the most out of Join Dementia Research.

You may have seen in the news recently that there have been some disappointing results in a couple of large dementia drug trials. Although this can be disheartening, it is only through research that we can learn what works and what doesn't in the fight against dementia. The important thing is to keep looking at different treatments and types of care, and to keep trying new things in order to beat dementia once and for all. And to achieve that goal the most important thing is you - the volunteers.

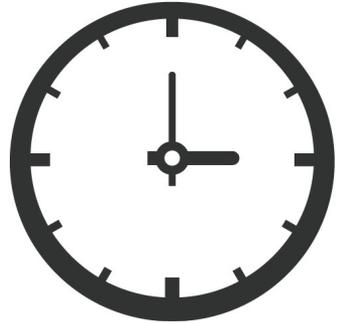
Dr Peter Arthur
Clinical Lead, Mersey and Cheshire Strategic Clinical Network for Dementia
Joint clinical research lead in Dementia, NIHR North West Coast



ARE YOUR DETAILS UP TO DATE?

Circumstances change for everyone over time. If your Join Dementia Research account isn't accurate, you could be missing out on matching with new studies or matching to the wrong ones.

In order to get the most out of your Join Dementia Research account, and to have the best chance of being matched with the right studies, we are kindly asking all Join Dementia Research volunteers to log in to your account and spend a few minutes ensuring that all of your details are up to date.



To update or check your details, you can get in touch with one of our helpdesks (details at the end of this newsletter). Alternatively, log in to your Join Dementia Research account at: www.joindementiaresearch.nihr.ac.uk/loginform

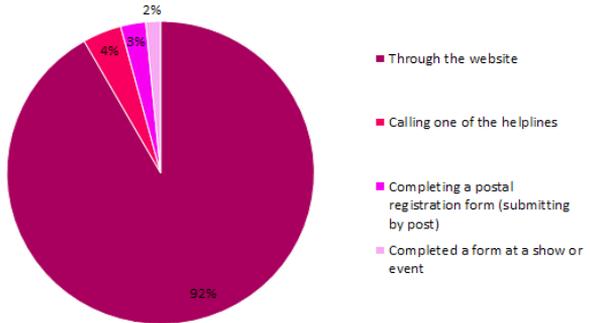
AUTUMN JOIN DEMENTIA RESEARCH SURVEY RESULTS

Many thanks to all those who completed our survey which featured in the Autumn 2016 newsletter. We had almost 1000 responses.

Some key findings included:

- 85 per cent didn't know how to get involved in dementia research before hearing about Join Dementia Research
- 66 per cent of people believe Join Dementia Research has made it easier for them to take part in dementia research
- 75 per cent of respondents consider Join Dementia Research has increased their awareness of what dementia research is going on
- 74 per cent of you would recommend Join Dementia Research to a friend, colleague or family member.

How did you register with Join Dementia Research?



It was also exciting to see a number of respondents were open to help promote research in the media. Please get in touch with us via the helpdesks or email us at comms.jdr@nihr.ac.uk if you would like to pursue this interest.

LATEST JOIN DEMENTIA RESEARCH STUDIES

There are always a variety of new studies being added to Join Dementia Research. Below are just a few of the most recent ones that are looking for participants. To see if you are eligible to take part in these, or any other studies that are currently on the system, simply get in touch with one of the helplines overleaf or log in to your account online.

LINKAGE Camden

Delirium is a medical term used to describe a change in brain function which makes a person become suddenly confused. There is evidence that delirium may cause permanent damage to the brain and could make people more likely to develop dementia in the future or exacerbate an existing dementia diagnosis. This study is looking to further understanding of the development and nature of delirium, as well as its potential effects on cognition and memory.



This study is currently recruiting participants from the Camden area.

Online Communication in Everyday Social Life



People who support, care for, or represent people with dementia respond to the situation in very different ways. One challenge that carers often face is in maintaining social relationships or making new relationships.

This study is looking to understand if there are technologies that can help carers socially by helping them meet others as well as provide information and support.

The study team are interested to hear from anyone in the UK over the age of 18 who cares for, or represents a person with dementia.

Spatial Navigation in Pre-symptomatic Alzheimer's Disease

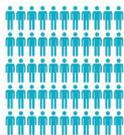
Getting lost is one of the most common and distressing symptoms for people living with dementia, and for their families. This study is looking at the link between spatial navigation and ageing.

This study is taking place in the Norwich area and participants will need to be based within a 20 mile radius.



JOIN DEMENTIA RESEARCH IN NUMBERS

These statistics are accurate as of 4 April 2017



27,473
total volunteers



47,458
screenings



7,264
participants that have enrolled
in studies to date



26%
of volunteers have
participated in a study



137
Studies have recruited



99
Studies currently open
to recruitment



761
trained researchers
using the service



171
NHS, University & commercial sites
have recruited using the system

TELL US WHAT YOU THINK

We are always looking for ways that we can improve our service. We would love to hear your feedback on this newsletter as well as finding out about your experiences of registering as a volunteer and being part of the Join Dementia Research initiative. Please provide us with your feedback at: bit.ly/SpringNewsletterFeedback or you can write to us at the address below.



GET IN TOUCH

To update your information on Join Dementia Research, please call one of the helplines:

Alzheimer Scotland: 0808 808 3000

Alzheimer's Research UK: 0300 111 5 111

Alzheimer's Society: 0300 222 1122

Calls to Alzheimer Scotland are free, calls to other Helplines cost no more than a national call from any type of phone or provider and calls are included in any free call packages on landlines and mobiles.

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Our mailing address is:

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